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Conference Abstract

## Tyze: Care, connect, contribute

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## Abstract

Research repeatedly verifies the old adage - a faithful friend is the medicine of life - and indeed there is bountiful evidence that we live longer, get sick less often, and heal more quickly when we have a supportive social network. Our formal systems of care frequently operate in isolation from the powerful human ties that help to keep us well. These systems are constructed on a professionally dominated paradigm that focuses on doing things for us and to us, as efficiently as possible. This paradigm, so very effective in acute and emergency situations, is ill suited to complex health and social challenges.

The spiritual and emotional nourishment, the daily monitoring and support, and the deep knowledge of our personal preferences and needs that are required to achieve true well being, cannot be provided by health and social care practitioners working in prescribed hours, away from our homes and loved ones. Instead we must look for solutions that provide older adults with flexible, responsive, individualized care. One answer is the use of online, personal networks that bridge formal and informal systems of care, so that people can work together to provide individualized care.

Personal networks deliver communication channels within a private, customized environment, so that health care practitioners can communicate seamlessly with the friends, family and other professionals involved in providing care. They are most powerful in their ability to build strong, meaningful communication channels between people who might otherwise not have the opportunity to connect. With everyone sharing ideas and information, work is distributed and the primary caregiver always knows who to turn to for extra help.

One example is the story of Charles, who was eighty-seven when his health took a turn. It started with congestive heart failure, then circulation problems and increasing forgetfulness. His children lived overseas and wanted to find a way to connect and collaborate with their Dad's caregivers. It was his son John who suggested setting up an on line personal support network for their Dad. At first his sisters didn't like the idea, but it took less than a week for the network to prove its usefulness. As well as John and his sisters, the network linked Charles's osteopath and a neighbour. In his first message

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on the network, the osteopath reported that although Charles was eating well, he had recently spent a whole day in bed, and he seemed to be feeling a bit lonely. The neighbour posted a message, saying that Charles had been prepping for their weekly phone calls by getting the morning newspaper to check the date, and writing down what he wanted to say in his diary. John and his sisters quickly looked for ways that they could collaborate with local caregivers to improve Charles' care. Soon the network grew to include other family members and neighbours who found that the on line network made it easy to offer help without feeling like they were intruding. Everyone on the network could access care schedules and contact numbers, and it also became a place to share stories. John posted photos and stories about his Dad, that gave his caregivers a fuller picture of Charles. Later, with a diagnosis of dementia, the doctor suggested supports to help Charles stay in his own home. In a flurry of organizing, arrangements were made for caregivers to come every day. The osteopath helped the family navigate an unfamiliar healthcare system. In-home supports like motion and temperature sensors were installed with Charles, kids contributing their dad's preferences and routines, those essential details that made the technology effective. For Charles and his family, the on line network bridged the miles. Even if we weren't there ourselves, John says, we could support the people who were there with Dad. When they posted, we replied with thanks and encouragement. It gave a constant feeling of being involved that was empowering for all.

## **Keywords**

informal care, formal care, social network, care network, social network, Internet

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